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The harm principle and the best interests standard: are aspirational or minimal standards the key?

The best interests standard has endured a sustained critique both from bioethics, and recently from those drafting the United Nations Convention of the Rights of Persons with Disabilities (CRPD). At the heart of these critiques is a focus on either aspirational or minimal standards. Both aspirational and minimal approaches are imperfect: only by sustained empirical study of the complexities of decision-making processes in practice will we be able to judge if the best interests standard is a sustainable approach.

While Johan Bester directs welcome attention to conceptual problems with the harm principle (Bester, 2018), it is also interesting that Bester's explanation of children's best interests should involve 'reasonableness', which is frequently advocated in this context. The frequency with which reasonableness occurs invites an immediate clarification about the nature of any 'harm consensus' in bioethics. Undoubtedly there are many and vocal voices within paediatric bioethics, who argue for the harm principle. Yet, outside my recently cited use of the term 'harm consensus' in a past paper, the only empirical basis for asserting a consensus exists around the harm principle rests on McDougal et al's (2014) systematic review of bioethical reasons for overriding parental decisions. McDougal et al.'s conclusion is that "There is a substantial consensus among ethicists that harm is the central moral concept when judging the appropriate threshold for state intervention in parents' medical decision-making." (p.452). Yet McDougal et al. perhaps make too much of the common recurrence of harm in this context. Harm is mentioned by many (although not all) of the twenty sources they examine, yet it is rarely the sole moral concept in these analyses. Arguably, close examination of McDougal et al.'s sources shows a similar preponderance

toward a decision-making standard based on reasonableness (indeed, they cite the role public acceptability plays in Diekema's explanation of the harm principle. This concords with at least one view of reasonableness).

What we can say about the bioethical mainstream is that both reasonableness and harm are about establishing minimal standards for intervention in parental decisions, rather than pursuing more aspirational goals that might be understood by seeking 'the best'. However, suggesting a roll-back from the (potentially) more aspirational aspects of the best interests standard needs examination. Other developments in ethics and jurisprudence see aspirational goals at the forefront of critiques of the best interests standard. With 177 signatories, including the United States, Article 12 of CRPD advocates a "rights, will and preferences" model for those with impairments to their decision-making competence (Gooding, 2015). Herein the emphasis is on supported decision-making, where, notwithstanding any mental impairment, it is incumbent on state parties to give sufficient support to every individual to allow them to overcome challenges to competence and make their own decision. Such a radical principle has been met with considerable scepticism. Critics argue, for example, that it will be impossible to apply such principles to those with disabilities so extreme that they impair consciousness. Yet the CRPD General Committee (2014: [21]) counter that

"Where, after significant efforts have been made, it is not practicable to determine the will and preference of an individual, 'best interpretation of will and preference' must replace 'best interests' determinations. ... The 'will and preference' paradigm must replace the 'best interests' paradigm

to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others”

The CRPD may yet collide with the harm principle. Article 7 of the convention extends these principles to children, likely with sufficient caveats to maintain the current status quo for infants, but potentially focusing opposition on situations where the harm principle is used to restrict the rights of older children (Alderson, 2017). Besides this, the CRPD provides a welcome opportunity to discuss the presumptive benefits of an aspiration (equality irrespective of disability) driving a decision-making standard, despite potential concerns about creating legal fictions.

Assuming a decision-making standard based on reasonableness or harm intends to avoid these fictions in the case of decision-making for children, it is salient to point out the potential for inconsistencies within, as well as between, approaches. Indeed, it is a valid question to ask just what a putative bioethical consensus might require in this context. Bester is but the latest commentator to have pointed out the very real likelihood that the harm principle might be interpreted differently by different people. Philosophical understanding of the vagaries of language works against consistent understanding: as Wittgenstein observed, concepts are not connected by some single, essential element, but by overlapping elements, some or all of which may be absent in one or other definition. This is a substantial criticism that should pour cold water on the idea that there exists any one concept that is easier to detect and more consistent to apply than the best interests test. Such an empirical claim been repeatedly made for the harm standard but there is little to show this is the case. On the other hand, the ‘problem’ of indeterminacy may be less severe when proposing an aspirational standard rather than a minimal standard. In these cases,

indeterminacy has a potentially welcome effect of allowing a decision-maker to flexibly draw on one or more guiding principles, depending on the situation at hand. In some cases, the harm standard *is* advocated as an aspirational standard (McDougall, 2016), and potentially an aspirational basis could also be made for reasonableness. Yet the grounds for this aspiration – such as, potentially, the need for family intimacy or the need for diverse types of upbringing – require robust philosophical undergirding. Importantly, such philosophising must attend to the realities of children’s healthcare, where, for example, the empirically ascertainable goods of medical treatment must collide with theoretical goods like religious welfare.

One way we might throw philosophical light on the realities of decision-making in practice is to undertake empirical studies specifically aimed at bioethical theory – so called empirical bioethics (Ives et al., 2018). Standards in practice are little surveyed, but recent studies in end of life decision-making (de Vos et al. 2015; Birchley et al. 2017) indicate that clinicians already allow a wide latitude of parental discretion. Whether such findings help make a substantial case for the harm principle or for reasonableness is open to question. Such findings potentially communicate a degree of professional openness to a *laissez-faire* approach to the welfare of children that may be supportive of a minimal standards approach. Yet, while this may be congruent with increasing the scope of parental rights, a willingness to disregard children’s interests in favour of the perceived interests of their parents may have more complex causes in the case of end-of-life decisions. Here, clinicians must sensitively balance the harms to the child that will ensue from overtreatment, with the potential lifelong benefits to parental mental health of a decision that parents trust was the best one. The studies indicate clinicians are adamant that they are the final decision-makers in this situation. Far from simply following the parental view of the good, they act in a softly

paternalistic manner to minimise harms and maximise goods for both the parents and the child. All this indicates a situation which is, as Bester quite correctly asserts, highly complex. There are dangers in advocating experimental changes to policy in the face of such complexity, and Bester is correct both to question the harm standard, and to suggest reforms rather than revolutions in operationalising best interests. Yet the most imaginative and helpful understandings of what is at stake when making decisions about children will come from engaging deeply with practice. To this end, with colleagues from law and bioethics, I am a collaborator in a major new empirical ethics project, funded by the Wellcome Trust. Over the next five years, *BAlancing Best interests in health care, Ethics and Law* (BABEL) (Huxtable et al. 2018) will be exploring the way the best interests standard – and its mooted alternatives – is used and understood in legal and medical decisions, not just for children, but throughout the life course. We aim to provide a venue for international discussion that can capitalise on the position of bioethics as a forum for the diverse experiences and opinions of patients, clinicians, lawyers, philosophers, theologians and social scientists. BABEL asks which factors and values should be considered when we use the best interests standard, who should be involved, and indeed whether the best interests standard is ultimately a sustainable approach. Bester's paper, by exploring both the weaknesses of the harm principle, and providing worked examples of the use of reasonableness in reaching best interests determinations, offers valuable critique and reflection on these ongoing issues.

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